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Issues

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13. Abstract With the continuing shift of cancer care to community-based care the necessity to develop programs that enable the family to meet patients' needs for support and assistance is of paramount importance. The overall purpose in conducting this exploratory investigation is to obtain information that will: identify adult daughter caregivers in need of psychosocial support interventions to enable them to meet their mothers' needs for illness-related emotional support and assistance; reduce daughters' emotional stresses associated with this support role, and, enable the daughters to continue their caregiving role. To accomplish these objectives we are collecting data from a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. The patients and their daughters each complete a questionnaire. The daughters also participate in a focused interview. Activities for Year 2 have focused on the continuation of the data collection effort and preliminary analyses of the qualitative interviews. To date, 32 patient-daughter dyads have been accrued into the study. The activities initiated during Year 1 have continued through Year 2 and will be ongoing through Year 3. The data being collected is informing our understanding of the psychosocial impact of cancer on the family.				
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INTRODUCTION

Life expectancy has increased dramatically in recent decades, producing an equally impressive expansion in the size of the elderly population. However, little attention has been given to cancer in the aged. Even less is known about the psychosocial problems experienced by older breast cancer patients and their families, as very little empirical research has focused on understanding the dynamics of older women's support networks. In particular, adult daughters, who are likely to be a primary source of support and assistance to older women, have not been a focus of research investigations or supportive services although they are likely to experience a high demand for emotional support themselves. The overall purpose in conducting this exploratory investigation is to obtain information that: identifies adult daughter caregivers in need of psychosocial support interventions to enable them to meet their mothers' needs for illness-related emotional support and assistance; reduces daughters' emotional stresses associated with this support role; and, enables the daughters to continue their caregiving role. To accomplish these objectives we are collecting data from a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. The patients and their daughters each complete a questionnaire. The daughters also participate in a focused interview. The activities for Year 2 have adhered to the research accomplishments scheduled for Year 2 in the Statement of Work. Specifically, Year 2 activities have focused on the continuation of subject recruitment and data collection, processing of the qualitative data, coding and preliminary analysis of the focused interviews, and the dissemination of study findings. To date, 32 patient-daughter dyads have been accrued into the study. Thus, the activities initiated during Year 1 have continued through Year 2 and will be ongoing in Year 3.

BODY

As reported in the Year 1 Progress Report, the following Tasks 1-4 were completed in Year 1:

- Task 1: Obtain access and prepare case accrual*
- Task 2: Prepare patient and daughter questionnaire collection*
- Task 3: Prepare focused interview data collection*
- Task 4: Design data management procedures*

The research accomplishments conducted during Year 2 (i.e., Tasks 5-8) have adhered to the approved Statement of Work. Activities related to these tasks have progressed and are ongoing. Specific details are provided below, organized by task.

- Task 5: Subject recruitment and data collection, Months 4-30*
 - a. Potentially eligible cases identified from ongoing review of clinic and hospital records*
 - b. Potentially eligible patient-daughter dyads contacted, screened and accrued*

- c. *Questionnaire data collected from patient-daughter dyads*
- d. *Focused interviews conducted with caregiving daughters*

Accrual is ongoing to obtain a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. Potentially eligible patients are identified from continuous review of the breast cancer patient population at the Herbert Irving Comprehensive Cancer Center, whose catchment area includes diverse socioeconomic and racial/ethnic neighborhoods. Permission to approach potentially eligible patients (i.e., diagnosed with breast cancer, in active treatment, aged 60+) is acquired from the patient's physician. Once permission is received, these patients are sent a letter informing them about the study. Included with the letter is a return post card with a check-off for persons who do not wish to be contacted. A clinician researcher then contacts potential participants by telephone to discuss the study further, determine their eligibility and, if they are interested in participating, determine whether the patients have a caregiving daughter who is 21+, a biological daughter, does not have a history of cancer and is involved in providing practical assistance and support to the patient. The clinician researcher then obtains permission from any patient who is eligible and interested in the study, to contact the daughter for study participation. The daughter is then sent a letter, followed by a phone conversation with the clinician researcher about the study. Only those patient-daughter dyads in which both members are willing to participate are accrued.

Table 1 presents the distribution by eligibility and participation status of the pool of potentially-eligible patient cases identified to date. As can be seen, the eligibility status of 50% of the patient pool could not be determined, primarily due to patient refusal to be contacted (n=61) or patient/daughter refusal to be screened (n=35). For an additional 24 cases, the patient was unable to be reached, and in three instances the patient died prior to being contacted.

To date, from the pool of patients, about a third (34%) were determined to be ineligible for the study. The major reason that a patient was ineligible was that she did not have a daughter (n=57). The second ineligibility reason was that the patient's daughter was not a caregiver to the mother (n=24). There was also one case in which the patient did not reside in the U.S. permanently and was only in residence while receiving treatment for her breast cancer. Generally, once an eligible patient was identified, the daughter was also found to be interested in participating in the study. About 78% of the eligible patient-daughter dyads agreed to participate in the study (n=32).

To date, we have accrued 32 dyads. Thirty-two patient questionnaires have been completed, 30 daughter questionnaires have been completed and 30 focused interviews have been conducted.

Table 2 depicts the distribution of the patient sample (n=32) that has been accrued into the study to date. In keeping with the racial and ethnic mix of the hospital catchment area, 72% of the patients are white, 25% are Hispanic and 3% are black. Almost half of the patients (47%) are currently married. Another 28% are widowed, and 22% are divorced or separated. With the addition of new participants in this second year of the study, the sample is more balanced in

**Table 1: Elderly Breast Cancer Patients Contacted in Year 2 by
Eligibility and Participation Status (N=246)**

	<u>%</u>	<u>(n)</u>
Eligible Patient-daughter dyads (n=41):		
Patient & daughter accrued	13	32
Dyad eligible, daughter refused	3	8
Dyad eligible, patient refused	<1	1
 Ineligible patient-daughter dyads (n=82):		
Patient resides outside of U.S., in U.S. to receive treatment	<1	1
Patient does not have a daughter	23	57
Patient has a daughter, but daughter does not provide caregiving to patient	10	24
 Unknown eligibility (n=123):		
Patient refused contact, returned postcard checking off option stating "DO NOT CONTACT"	25	61
Patient/dtr refused to complete screener form	14	35
Unable to contact	10	24
Patient died prior to screening	1	3

terms of age, with 50% of participants among the young-old (i.e., 60-69 years old), and 50% among the old-old (i.e., 41% aged 70-79 and 9% aged 80 or older). About two-thirds of the patients (69%) have been diagnosed with local breast cancer. While all of the patients have received surgery for their cancer, 38% of the patients have also had radiation and 28% have had chemotherapy.

Task 6: Data processing of quantitative (questionnaire) data, Months 6-30

- a. Patient and daughter questionnaires edited, coded and data entered into computer databases*
- b. Data cleaning of questionnaire data implemented*

Once a questionnaire has been completed, it is edited and coded; the responses are then entered in a computer database. As part of the data entry program, a variety of data cleaning and data checking procedures have been written into the program. This ensures that out-of-range punches, miscodes and "Does not apply" sections are identified and errors are corrected.

Task 7: Coding and textual analysis of qualitative (focused interview) data, Months 10-33

- a. Transcripts of audiotaped focused interviews entered into computer text files*
- b. Provisional coding scheme developed for focused interviews*
- c. Reading, reviewing and re-reading of focused interview transcripts*
- d. Core codes and subcodes expanded upon and revised*
- e. Transcripts re-read and relevant textual material assigned codes and subcodes*
- f. NVivo codes inserted into computer text files of focused interviews*

The focused interviews conducted with the daughter are audiotaped, with the daughter's permission. These audiotapes are then transcribed and entered into computer text files for later analysis and textual coding. Preliminary cases have been transcribed and the development of a provisional textual coding scheme has begun and is ongoing.

Specifically, material from interview transcripts is read, reviewed, and coded by two independent readers. To ensure that the coding scheme for the codes is valid (well grounded in the data and supportable) and reliable (consistent in meaning), it is developed in a systematic and well-developed manner. Initially, readers identify broad themes relevant to the foci of analysis. These themes are then assigned "core" codes (1). In turn, "secondary" codes may be developed that represent more specific or restricted aspects of the theme, contextualize the theme, or indicate daughters' personal meaning underlying the theme.

A provisional coding manual has been prepared, that includes a common set of themes derived from the interview data and a common set of criteria to assign numeric values to the themes, core codes, and secondary codes. Working independently, readers assign numeric values to each

**Table 2: Sociodemographics of Elderly Breast
Cancer Patient Sample in Year 2 (N=32)**

	<u>%</u>	<u>(n)</u>
Race/Ethnicity:		
White	72	23
Hispanic	25	8
Black	3	1
Marital Status:		
Married	47	15
Widowed	28	9
Divorced	13	4
Separated	9	3
Never married	3	1
Age:		
60-69	50	16
70-79	41	13
80-89	9	3
Extent of Cancer:		
Local	69	22
Regional/Metastatic	31	10
Type of Cancer Treatment:		
Surgery	34	11
Surgery & Radiation	38	12
Surgery & Chemotherapy	28	9

identified segment of text. Meetings are conducted periodically to discuss, expand upon, and revise the core codes and subcodes. As new themes, refinements, or new aspects of previously identified themes emerge, the coding manual is revised and additions/modifications to the coding are applied retroactively as necessary.

Coding discrepancies are resolved through joint discussion and verification of the text with other interviews having the same code, in an effort to arrive at a consensus between the readers about the appropriate coding. In keeping with the principles of grounded theory (2), any additional themes emerging from the text may inform the interview protocol. If deemed necessary, these are integrated into the interview topic guide.

The qualitative data collected from the focused interviews reflect the study goal of discovering the respondents' personal "definition of the situation" and understanding their lived experiences. The interview process aims to elicit the meanings that daughters ascribe to the events and circumstances that may shape these processes (1, 2). Thus, the topic guide includes discussion of issues related to (a) diagnosis, illness, and treatment (e.g., circumstances leading to the mothers' diagnosis, daughters' reactions to their mothers' illness and treatment experiences); (b) cancer risk (e.g., daughters' perceived vulnerability to cancer, their health monitoring plans and disease-prevention practices); (c) caregiving (e.g., daughters' caregiving burden, their need and receipt of emotional support and practical assistance); (d) lifestyle changes (e.g., changes in family roles and functioning since the inception of the illness, impact of the illness on daughters' quality of life, work, and future goals); and (e) fertility/child-rearing (e.g., the effects of their mothers' breast cancer on daughters' fertility decisions and on child-rearing practices).

Task 8: Dissemination of study findings, Months 12-36

- a. Construction of analytic topic files from qualitative data*
- b. Construction of analytic data files from quantitative data*
- c. Analysis of the quantitative and qualitative data carried out*
- d. Manuscripts, presentations, annual and final study report prepared*

As described above, topic file material is subjected to thematic analysis by independent readers. These codes are intended to be used in conjunction with NVivo, the qualitative software that is being used to assist in the qualitative data analyses. NVivo supports code-based inquiry, searching, and theorizing, combined with the ability to annotate and edit documents. It can produce frequency counts for core or secondary codes by case, designated subgroups, or total data file. Text can be searched for and transported by a core or secondary code or any code combination. Progress is ongoing with regard to importing the coded transcripts into NVivo, in order to conduct text searches, text retrieval, and identification of themes, concepts, and variables. In addition, quantitative data obtained from the patient and daughter questionnaires can be accessed through NVivo to contextualize the analysis of the quantitative data and permit exploratory subgroup analyses. That is, any measures collected as part of the questionnaire can be imported through NVivo into the qualitative files.

A poster entitled "Psychosocial Concerns Experienced by Caregiving Daughters" is to be presented at the 2002 Era of Hope Department of Defense Breast Cancer Research Program meeting. This paper describes preliminary findings that have emerged from the interviews with caregiving daughters, including their heightened sense of vulnerability and their resultant health-monitoring behaviors. (See attached abstract.)

An oral presentation, entitled "Aging Families and Breast Cancer," will be presented at the 2002 annual meeting of the American Public Health Association in November. The presentation discusses the ways in which women's perceptions of their own cancer risk can affect the quality of their care provision to an elderly mother. It also examines the impact of the quality of the patient-caregiver relationship on the patient's psychological functioning. (See attached abstract.)

YEAR TWO: KEY RESEARCH ACCOMPLISHMENTS

- Continued patient-daughter dyad accrual
- Continued data collection with patients and daughters
- To date, conducted 32 patient telephone interviews (structured questionnaires)
- To date, conducted 30 daughter face-to-face interviews (structured questionnaires and focused interviews)
- Edited, coded and data entered patient and daughter questionnaires
- Used SPSS systemfile for patient questionnaires
- Used SPSS systemfile for daughter questionnaires
- Transcribed daughter focused interviews
- Added to archive database of daughter focused interview transcripts
- Created provisional textual coding scheme
- Revised topic guide to reflect preliminary study findings
- Began dissemination of study findings at conferences

YEAR TWO: REPORTABLE OUTCOMES

Year 2 reportable outcomes include the expansion of databases, as more patient-daughter dyads are accrued and interviewed throughout Years 2-3, and the initiation of dissemination activities. These activities are listed below:

- SPSS systemfile of patient questionnaire data (n=32)
- SPSS systemfile of daughter questionnaire data (n=30)
- Archive database of word processed transcripts of daughter focused interviews (n=30)
- Poster to be presented at the Era of Hope Department of Defense Breast Cancer

- Research Program meeting
Oral presentation at the annual conference of the American Public Health Association

CONCLUSIONS

The Year 2 field experiences continue to affirm the feasibility of the study procedures (i.e., case identification, sample accrual, and data collection). They also indicate that daughters and mothers are willing to participate in the study and find it meaningful to share their experiences.

The data are starting to inform our understanding of the psychosocial concerns impacting caregiving daughters, following their mothers' diagnosis of breast cancer. Preliminary analyses indicate that a rich data set is emerging. For example, daughters in the sample spoke of their mothers' diagnoses as eye-opening events that made them aware of their own vulnerability. For some, this heightened sense of vulnerability translated into behavioral changes expressed as a resolution to adhere to screening guidelines and engage in health-promoting behaviors. Several daughters acknowledged that this awareness of their increased risk was associated with excessive worry and anxiety, expressed in hypervigilant monitoring. Finally, those with an extensive family history of breast cancer viewed their mothers' diagnosis as expected and inevitable, and often presented a stoic attitude about their own level of risk.

In keeping with the objectives of the study, these data are part of our effort to assemble information that can inform the development of a risk profile to target daughters at need for educational intervention and professional assistance in order to enable them to retain their caregiving role, perform their support responsibilities adequately, and meet their mothers' needs for support and assistance.

The data collection effort continues and it is expected that project activities will proceed as outlined in the Statement of Work for Year 3.

REFERENCES

1. Blumer, H. (1969). Symbolic interactionism: Perspectives and method. Englewood Cliffs: Prentice Hall.
1. Strauss A. (1987). Qualitative analysis for social scientists. New York: Cambridge University Press.

APPENDICES

<u>Appendix</u>	<u>Title</u>
A	Columbia University Study Protocol Reapproval Letters
B.	Abstract for the Era of Hope 2002 Department of Defense Breast Cancer Research Program Meeting
C.	Abstract for the 2002 annual conference of the American Public Health Association

COLUMBIA UNIVERSITY
COLLEGE OF PHYSICIANS & SURGEONS

COLUMBIA-PRESBYTERIAN MEDICAL CENTER INSTITUTIONAL REVIEW BOARD
CPMC IRB

March 11, 2002

Victoria Raveis, PhD
School of Public Health
100 Haven Ave. Ste. 6A (Tower 2)

RE: CPMC IRB # 9585 "AGING FAMILIES AND BREAST CANCER: MULTIGENERATION ISSUES"

Dear Dr. Raveis:

The research study involving human subjects described in the protocol you recently submitted for Institutional Review Board review was re-approved at the convened IRB meeting on 03/06/02.

The IRB approves this research protocol for the period of 03/29/02 to 03/28/03. This date of re-approval for your protocol is the date to be used on all certification forms (including HHS Form 310) or letters forwarded to funding agencies.

Please note:

- The CPMC IRB expiration date for this study is 03/28/03.

We will forward renewal information to your office about 60 days prior to the study's new expiration date of 03/28/03. To insure that approval for your study does not lapse, please submit renewal documentation at least thirty days prior to this expiration date.

All adverse events, amendments, modifications and advertisements of any type must be submitted to the IRB office for review.

Sincerely,



Paul Papagni, JD
Executive Director, CPMC IRB

PP/at

cc: IRB File
Elizabeth Kaufman, Cancer Center

encl: English consent (1)

THE CPMC IRB EXPIRATION DATE FOR THIS STUDY IS 03/28/03



HERBERT IRVING COMPREHENSIVE CANCER CENTER
Columbia University
Clinical Protocol Office

February 20, 2002

Victoria Raveis, Ph.D.
SPH/SMS
100 Haven Ave suite 6A

IRB #9585, CPMC: Aging families and breast cancer.

Dear Dr. Raveis:

The above noted protocol was reviewed for annual approval at the February 14, 2002 meeting of the Cancer Center Protocol Review Committee. It has been noted from the renewal form that the target accrual has increased to 240. There were no other outstanding issues. Therefore, the study was re-approved for one year.

As you know, the study will still require IRB approval before you can continue to enroll patients or collect data.

Sincerely,

Elizabeth Kaufman, M.P.H.
Director

EK/lb

Cc: IRB

PSYCHOSOCIAL CONCERNS EXPERIENCED BY CAREGIVING DAUGHTERS

Victoria H. Raveis, Ph.D.; Tina Sapienza, C.S.W.,
Monique Carrero, M.A., Sheindy Pretter, Ph.D.

Columbia University, Mailman School of Public Health

Vhr1@columbia.edu

Adult daughters are likely to be a primary source of support and assistance to older women diagnosed with breast cancer, but they have not been a focus of research investigations or supportive services. However, caregiving daughters are likely to be experiencing a high demand for emotional support themselves. The anxiety and concern these women are experiencing over their familial risk status may be compounded by the emotional stress and strain of providing assistance and support to their ill mother, as well as having to deal with the intimate knowledge of their mother's cancer experience afforded by their caregiving experiences. Interviews are being conducted with a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. As part of the data collection, daughters complete an unstructured open-ended interview. The interviews are audio taped, subsequently transcribed into interview text files and then content analyzed. Data collection is ongoing, but analysis of the interviews conducted to date inform our understanding of the psychosocial concerns impacting the caregiving daughters following their mother's diagnosis of breast cancer. The daughters in the sample talk about their mother being diagnosed with breast cancer as an event that opened their eyes and made them realize their own vulnerability. This heightened sense of vulnerability is translated for some of these caregiving daughters into behavioral changes expressed as a resolution to adhere to screening guidelines and engage in preventive health behavior. Even those women who previously were aware of the importance of regular check-ups and mammography now see their value brought home. For some women this translates into their being more proactive about their health. This awareness of increased risk is also associated with heightened worry and anxiety and can be expressed in hyper vigilant monitoring. Some caregiving daughters, who have an extensive family history of breast cancer, view their mother's diagnosis as an expected, inevitable event. These daughters often present a stoic attitude about their own risk. The breast cancer diagnosis has also impacted their view of their children's risk and their resultant monitoring behavior.



Paper #47997

Aging families and breast cancer

Victoria H. Raveis, PhD, Joseph L. Mailman School of Public Health, Columbia University, Center for Psychosocial Study of Health and Illness, 100 Haven Avenue, Suite 6A, New York, NY 10032

Limited attention has been given to cancer in the aged, especially among various minority populations. Hispanic elderly primarily rely on family for care in times of illness and female relatives are likely to be the primary source of support and assistance. However, first degree relatives of breast cancer patients are at increased risk for breast cancer themselves. This heightened sense of risk has been associated with increased anxiety levels. A substantial proportion of women at-risk for familial breast cancer hold exaggerated perceptions of their risk and for some the perceived threat is associated with a paralyzing sense of cancer-related worry that severely impacts their ability to function on a daily basis. The anxiety and concern these women may experience may be exacerbated by the strain of providing assistance to their ill mother. Those who are extremely distressed and worried may be incapable of providing the assistance and emotional support their ill parent requires. At-risk women's level of psychosocial adjustment to their familial risk status may also have an adverse effect on their interpersonal relationship with the mother, contributing to unmet patient needs and conflicted support. Such occurrences can impede a cancer patient's recovery. This presentation will discuss how women's perception of their cancer risk effects the quality of their careprovision to their elderly mother. It will also examine the impact of the quality of the patient-caregiver relationship on the older patient's psychological functioning. The data is drawn from interviews conducted with a sample patient-caregiving daughter dyads (n=40).

Abstract ID#: 47997

Password: 791906

Program Selection: Gerontological Health

Topic Selection: Formal and Informal Caregiving

Keywords: Breast Cancer, Aging

Learning Objectives: Attendees will: 1) Understand the impact of breast cancer on the aging family 2) Appreciate the psychosocial stresses of informal caregiving 3) Appreciate the the impact of perceived risk of cancer on the quality of the patient-caregiver relationship

Submitter Email: vhrl@columbia.edu

Target Audiences: Counselors and social workers working with other cancer patients and their families
Oncologists treating older patients Pastoral care workers working with older families Genetics counselors

Presentation Format: NoPreference

First Author

Presenting

Victoria H. Raveis, PhD

Joseph L. Mailman School of Public Health

Columbia University